

Summarized Timeline:

- * Jan. 31, 1979 (Wednesday) -- born / severe allergies to mold, pollens, grasses (should have been born in a different place - maybe - but I didn't pick) :)
- * 1979 - 1990 / 1991 (Inpatient multiple times per year for severe asthma / pneumonias / bronchitis) / recurring ear and sinus infections
- * 1990 / 1991 Prescribed Very High dose of Ceclor - I remember puking up what looked like coffee grounds for days in a row -- possible part of problem at some point
- * 1992 - 1997 Dealing with a lot of psychological childhood trauma from things I won't note here - fewer physical health problems but they were still there
- * 1997 Wisdom teeth out (2 had to be cut out of bone - 2 had to be just pulled)
- * 1997 - 2003 Purdue (fewer asthma and allergy problems - lived in W. Lafayette instead of Ohio River Valley), had some weird EBV-like virus while there.
Also - had gotten bit by a Brown Recluse spider while I was there and had to have a surgery (had to remove a small area of 'flesh' from my leg.
I had to pack this wound with 6 feet of strip gauze each day while it healed from the inside out - it was probably about 3/4 of an inch deep (maybe 1/2 inch).
I have pictures somewhere but they are kind of gross haha.
- * 2003 - 2006 Grad school, and also working full time....first as a Retail Store Manager for Bridgepointe, Goodwill, and Easter Seals. Then as the Office Manager for the American Red Cross in the department of Health, Volunteer, and Youth Services (I had 5 programs I managed there - CNA program, CPR program, Volunteer Program, CPR Instructor Program, and I cannot even remember the other one now!), and later I was a Retirement Service Center Specialist at Mercer Human Resource Consulting (a subsidiary of MMC) doing retirement plan valuations (that was the most blah job I ever had).
- * In 2005 I was hospitalized for an asthma attack (inpatient)
- * In 2006, one of my best friends hung himself, on Thanksgiving Day
- * Did not have a single cavity in my life until after I was 20 years old
- * Started having more, and more, and more back issues / spasms sometimes lasting for weeks basically incapacitating me
- * 2007 Moved 'to the country' to a 14 acre prior horse-farm. Had bought land to start Grateful Goat Vineyard & Winery (Picked the name b/c Grateful Dead fan and I wanted goats - which I later owned (Nigerian Dwarf Goats). Working full time, as National-On-Premise Coordinator for American Beverage Marketers

though, so I spent lots of time using a wet/dry vac, a steam cleaning vacuum type machine, and trying to dry out wood 2x4s that had gotten wet - sometimes with wine, sometimes with spoiled wine (acetic acid), sometimes with water, sometimes with juice...would have been the perfect breeding ground for a million different kinds of bacteria (not literally - well actually - probably...)....anyway 'cork taint' is caused by a chemical called Trichloroanisole (TCA) - because I used natural cork - and customers demanded it... to avoid cork taint, you have to avoid the use of chlorine - so the water had a special filter we bought to remove chlorine, couldn't use any cleaning products containing bleach or chlorine ions, etc.... interesting side note: most natural cork is harvested from trees grown in Portugal. The trees are generally 55 years old before they are harvested for the first time, and can be harvested about once every 9 years. Cork trees are Cork Oak trees.

* 2009 On 4/14/2009 -- Spine Surgery -- Medical malpractice. L4/L5 and L5/S1 Microdiscectomy and Neural Decompression. Laser Minimally Invasive "Low-Risk" Surgery. By this point in time, I had had several months where I could not even walk upright for at least 2 weeks out of each month... When it was all said and done, the doctor had injured at least 33 other people, leading to the death of at least one, one former patient, not in the class action lawsuit that I was in, had previously won a 6 million dollar judgement against the doctor. She, as far as I know, has still also not been able to collect from him. This doctor lost his license in OH, lost his license in Indiana, and still practices in TX. The thought of him harming others makes me feel sick. The laser used during the surgery was not intended for use in the spine as it got too hot. The doctors brother was the lawyer for an 'institute' that rented space from the hospital. The doctors brother also apparently was providing legal counsel for the hospital. Neither the hospital, nor the doctor, nor the lawyer, had medical malpractice insurance. The doctor declared bankruptcy. The doctor and his brother were members of a trust held in the Cayman Islands with untouchable assets. The woman that won the \$6M settlement had the same lawyers that were chasing Bernie Maedoff's money - but as far as I know, she was not able to recover anything. She was no longer able to feed herself after the surgery. Of course, prior to me having the surgery, I did not know about any of this, or I would obviously have not gone through with it. I still beat myself up for having the surgery. I remember asking myself if I was sure I wanted to go through with it right before going into the OR.

Woke up from spine surgery in extreme searing pain. Was told it was 'normal', and that it would go away and ease in time...sent home to Louisville (2.5 hours in car). Got home - in SEVERE PAIN - left leg down to foot - couldn't dorsiflex left foot (for 10.5 months), left foot felt like a block of wood, extreme burning pain...etc...had a 10 DAY SPINAL HEADACHE FROM HELL. When I got home realized couldn't lift head off pillow. Also it seemed I'd

possibly 'wet myself'. Went to local urgent care - they tested and told me it was CSF. Doctor (surgery doctor) called in LevaQuinn in case of possible infection....that was before the black box warning on fluoroquinolones....I would live in uncontrolled neuropathic pain until 3/27/2010.

My doctors would not believe me how badly I was hurting, and despite me literally crying in agony, and my nervous system feeling like it was shrieking in horror, and me describing the pain as burning, shooting and stabbing pain, neither neurologists, neurosurgeons, or my primary care doctor at the time could identify it as neuropathic pain - nor felt it could have been related in any way to the spine surgery. I had to literally beg and plead -

I asked for Gabapentin or Lyrica and Elavil first, but no one would prescribe it for me (that is before it was even scheduled). Finally, the 2nd neurosurgeon

I saw in Louisville post surgery said he would prescribe me a one month one time fill of the lowest dose level of Darvocet. Well that really didn't do anything.

Well eventually, I did get a CRPS type I diagnosis for this, but not until I had been gaslit by the medical community for 8 years,

and told the pain was all in my head. I was still trying to work, and had opened the winery on 10.16.2009. In very late 2009, or very early 2010, I remember riding in to work with my ex-wife (we worked close to one another - so we rode together often - since we lived about an hour away - to save gas). I

remember telling her I just wanted to die. She didn't 'hear' me though - she did with her ears, but not with her mind.

Got flu vaccine: Relevant b/c 2009 flu vaccine linked to development of narcolepsy

* 2010 On March 27, 2010, drove to Cleveland, OH with my ex-wife. It was pouring down rain the whole trip. It was an 8 hour drive. I was wearing my TENS unit the entire time. There was a five alarm church fire with a church burning down in the pouring down rain when I got there. Ultimately, Cleveland Clinic said I would need to 'experiment with drugs until I find a cocktail that works for me - while working with a provider that would allow me a trial-and-error approach [I am still looking for this type of provider by the way] - because I would live in pain for the rest of my life. They did, however, put enough information in my record, for my PCP to finally allow me to try Gabapentin and Elavil...and that worked some for about a year and a half.

Nov. 2010 - took Radioactive Iodine to destroy thyroid gland for Grave's - could no longer take antithyroid meds safely - liver enzyme elevations

* 2011 January - bilateral foot pain - extreme burning - same but 'different' - 6 years later would be identified as small fiber neuropathy (and not psychiatric)

Saw multiple podiatrists, who all concurred, it was 'non-standard' plantar fasciitis. Had 4 rounds of steroid injections - obviously - didn't help

April 2011 - my child was born!! Due on Apr. 25, born on Apr. 26th. There were literal rainbows all around when we brought Jack (now Jacquelyn) home!

I was even worse fatigued...I thought well I have a thyroid problem, my levels are always too high or too low, and I have a new kid, and a business where I am working over 100 hours per week...so tried to excuse it as those things, myself - I was dismissive to myself!

* 2012 Later, however, I knew something was terribly wrong. Our mailbox was 900 feet away...I used to walk that walk daily many times over....I could no longer do it even once....I got weaker and weaker. PCP pushed me into pain management. Started taking oxycodone...later...higher doses...then fentanyl patches. Then fentanyl patches of higher strength.

* 2013 Summer 2013 Swiss Wine Festival - Last one we participated in. I had created a business that would run itself, had 40+ seasonal workers, 3 part-time staff there all the time, music (live) most weekends, attended 12 wine festivals each year, had one tasting room in the country, and one in the city....I had done a good job. It took me a long time to see it that way. I feel like I did a good job today, but still feel like I failed.

I was trying so hard to keep my marriage together, keep my family together, keep the business going, keep my workers paid, etc.. I had had many ticks that had gotten on me over the years, but the weaker I got, the harder it was to take care of myself.... in 2013...I knew that that was it....I wasn't healthy enough to continue... Closed the winery to the public in 2013 (License expired June 2014)....

* 2014 My ex-wife told me she wanted a divorce, but I was like 'why' I built all this for you basically - because that is what she said she wanted as a life...didn't matter in the end....I convinced her to try to give it a go with the business closed, but I was already sick. Later, she'd tell me that she never wanted to be with a 'sick' person. I told her my definition of marriage, and her definition are two separate things. Started to get so sick that I could not prepare meals, or walk to the bathroom, had to crawl, not strong enough to have enough sustained energy to brush my teeth - which was a problem - because one of the things that stood out the most - was that my gums would bleed A LOT and they were sinking and falling apart.... In May 2014, sold the old winery house in a matter of 6 days. We were working on closing on a 'short-sale' home in Memphis, Indiana - which we did by the time of the closing of the house we were selling. I felt like - finally - things were going to improve - but no....it wasn't in the cards....I was like I need help! But doctors didn't care - they couldn't find any abnormal labs - therefore I was crazy - medical gaslighting at its finest....my 3 year old had to help me take care of myself..

* 2015 Started researching everything again - found Dr. Jacob Teitelbaum who talks of recovery from fibromyalgia which I thought I had (and do). He recommends the S.H.I.N.E. protocol (supplements, hormones, nutrition, exercise - I forget what the I stands for. He also suggested stopping gluten and juicing foods. I was taking many supplements on my own (unable to work by this point), juicing foods, although it took every ounce of being within me to do anything, started eating gluten free, went to see my first functional medicine doctor in Cincinnati (Dr. Blatmann). Pain mgmt doctor suggested having all kinds of titers (lyme, rmsf, ebv, cmv, and some others the doctor refused to order). WB was neg. but I was already aware of the 2 schools of thought in medicine for Lyme. Developed cramp fasciculation syndrome during this time. High EBV titers suggestive of potential re-activation, CMV - same thing. I was reading heavy into human herpes viruses, and read about Shingles of course, and then a relationship of EBV, CMV, and HHV-6 to CFS/ME which I had gotten a dx of sometime around this time. I was pos. for HHV-6, and back then also for HSV-1...my immune system was wrecked. I've been gluten free since then...

Dx with Narcolepsy

* 2016 Saw a diff functional medicine doctor closer to home (and Asst. Dean at IU School of Medicine then) - so felt like he had some credibility. He was a friend of a friend of mine that owned a detox clinic. I was using medical cannabis around this time too, which was helping some, and doing yoga daily, and trying to eat all organic non-processed foods, and get rid of toxic chemicals as I had developed seemingly multiple chemical sensitivity syndrome. Made first trip to Mayo Clinic. Told them my history (I'd read maybe 10,000 pages of medical journals by then) - told them I thought I had small fiber neuropathy, erythromelalgia, fibromyalgia, and RSD/CRPS. They said patients aren't doctors and Dr. Google isn't a doctor either. I told them I only looked at pubmed.gov - to which they told me I wouldn't understand what I was reading - it was very insulting... They said 'we are the ones who will tell you what is wrong' - not the other way around - all I did was shake my head and say then why did you ask me what I thought was wrong if you did not want to hear it... They did a bunch of testing. Abnormal thermoregulatory sweat test, abnormal QSART, abnormal QST, but they weren't confident enough to write down sfm w/o the punch biopsy.

I saw a bunch of specialties there over a week, and they said they thought I had small fiber neuropathy, erythromelalgia, fibromyalgia, and they said a diff dx of RSD/CRPS-1. I had been there for a week, and they had actually wanted me to do a sural nerve biopsy - which I am glad I didn't do...they helped me get established at Washington University in St. Louis. I saw Dr. Pestronk there. He is up there in the same class of Dr. Oaklander in terms of SFN (Mass Gen for her - didn't get to see her though b/c of COVID). Dr. Pestronk said he could tell from the clinical picture that it was SFN. I went to Wash. U. twice. Had punch biopsy done - confirmed - non-length-dependend SFN - finally - a Dx! Mayo had said I could not have SFN and RSD/CRPS, but I knew better...

I asked Wash U., and was told it is possible, but it would be one very unlucky individual. Well, that's me.

* 2017 Went to International Center for RSD (CRPS) in Tampa, FL - and they did testing and confirmed my symptoms were consistent with RSD/CRPS.

Had Transient Ischemic Attack (TIA) in April 2017

* 2018 Had started on carbamazepine by now and was taking topamax and had tried some other combinations of things....had to eventually go off of them though...

Due to side effects. No matter how hard I tried, how many things I did right, I still could not recover, and still cannot recover - so something like Sjogren's, that I have a dx for, that is systemic, and progressive, makes sense...

* 2019 Started having major eye trouble - met a girl I dated pretty seriously for about a year and a half. She had a serious mental illness though that I did not know about at the beginning of that dating journey - she hid it well - severe BPD - and a few months after I broke up with her in early 2020, I learned she died by Suicide in (Sep. 2020)

Started exploring Mast Cell Activation Syndrome as I suspect I have that - learned I had hypogammaglobulinemia. Had IgM measured many times often coming back way low or even undetectable. Often IgG was only slightly decreased but enough to cause damage I think.

* 2020 Kept looking for answers - dx with Meibomian Gland Dysfunction and Dry Eye Disease / dry mouth/throat had always been blamed on being a mouth breather - I am thinking it was actually Sjogren's all along... trouble swallowing food got worse and worse and worse over this timeline...take pilocarpine so I actually have saliva now, and that aids a GREAT DEAL with swallowing food! It is the little things you take for granted!

* 2021 Started IVIG, at first, for autoimmune neuropathy (FGFR3 auto-antibody), and it has helped some autonomic dysfunction issues like syncope that I have had to deal with.

* 2022 Switched to having my GI doctor rx the IVIG so I could have some help in terms of patient assistance program. She prescribes it for the Gastroparesis issues I have. Late 2022 - dx with Sjogren's. Had met ACR criteria....ANA positive, SSA-Ro positive, Schirmer test score, high IL-6, high IL-10, abnormal SP-1 and CA-VI abx.

I don't have a dx for EDS, or for MCAS but suspect the possibility of both - they often occur with SFN and with Dysautonomia issues, and even with Sjogren's in a number of cases.

I have explored treatment for mold illness which often co-occurs with true long-standing chronic lyme infections or post-lyme-disease-syndrome cases. I have had a lot of the testing done - which much of, did come back as positive....

I'll send some labs a different time - this has gotten rather long - but is a good picture of how everything developed.

Article about Lyme manifesting as Sjogren's (NIH - 2019)

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6409830/#:~:text=Lyme%20borreliosis%20manifesting%20as%20Sj%C3%B6gren's,positive%20effect%20of%20antibacterial%20therapy.>

Sjogren's can be secondary to Lyme. I think that is probably what happened in my case - that the Sjogren's was triggered by the Lyme Disease - and that mold illness got thrown into the mix as well because that is common with Lyme. The health problems are so complex that nobody knows how to handle them - and they fall in between the cracks of between specialties.

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Lyme:

In 2017, the CDC said there were 3,000 cases per year...later...a year or two later....they upped it to 30,000 cases per year...now they say 476,000 cases per year....and they note that this number is likely under-reported....

JRF - I will let you form your own opinion - I've dug into some of this in the past, and know what I believe about the issue.

Plum Island:

[The Officially Ignored Link Between Lyme Disease and Plum Island](#)

Lyme Testing Specialty Labs:

<https://igenex.com/>

<https://www.arminlabs.com/en>

Common Post Lyme Disease Syndrome symptoms:

- Fatigue
- Cognitive dysfunction
- Headaches
- Sleep disturbances
- Migratory myalgia and arthralgia
- Numbness and tingling
- Neuropathic pain
- Depression and anxiety
- Musculoskeletal problems.⁴⁶

Note: Below -- ILADS stands for International Lyme and Associated Diseases Society

THE ILADS POSITION ON TREATING CHRONIC LYME DISEASE

Based on the extensive collective experience of ILADS members and a rigorous review of the broader scientific literature, ILADS maintains it is in the best interest of chronic Lyme disease patients for clinicians to offer additional treatment.⁵⁴ Taking into account the strength of the evidence addressing the effectiveness of antibiotic retreatment, the burden of disease in this patient population, and the risks associated with various antibiotic options, ILADS concludes that the very real consequences of an untreated chronic Lyme infection far outweigh the potential consequences of long-term antibiotic therapy. Further, we assert that although it is too early to standardize restrictive protocols, effective treatment options are available for these patients.

JRF - I think that Lyme causes damage to a-delta and c-unmyelinated nerve fibers (small fiber polyneuropathy), and that leads to autonomic dysfunction and dysregulation / disturbances / and leads to dysregulation of homeostasis as well on multiple levels. --- every common symptom of Post Lyme Disease Syndrome listed above is common to SFN ... I do not think this study has been done yet - but it would be very interesting to see results from such a study.

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